# I. Summary

## A. Background

From March through December of 2003, Public Health - Seattle & King County's HIV/AIDS Program and the HIV/AIDS Planning Council for the Seattle Eligible Metropolitan Area (EMA) conducted a comprehensive needs assessment of HIV/AIDS care services in King County. Quantitative epidemiological data, including current infection and case trends, had already been collected and analyzed by Public Health's HIV/AIDS Epidemiology Program and were used in this comprehensive process.

The 2003 Needs Assessment was a research and planning activity that sought to:

- identify the extent and types of existing and potential care service needs among persons living with HIV/AIDS in King County;
- examine the current service delivery system in the County, particularly the system's ability to ensure that persons living with HIV/AIDS can effectively obtain and maintain access to primary medical care and treatment;
- determine the extent of unmet needs in order to plan appropriate care services;
- analyze and compare two-year trends in service utilization, priorities and gaps, and
- develop quantitative estimates of the number of persons in King County who are HIV positive and aware of their serostatus, but not engaged in primary care.

The main objective of the 2003 Needs Assessment process was to provide data to inform decisions related to the Planning Council's prioritization of care services for the Ryan White CARE Act's Title I funding allocation process. (See Appendix A for a list of Planning Council-approved Ryan White service categories.) Additional goals of the project were to:

- assess the current Continuum of Care in Seattle-King County, with the goal of strengthening the system and working towards greater collaboration among diverse communities and service systems;
- provide legislatively mandated information to the federal Health Resources Services Administration (HRSA) on service needs and system response, and
- provide planning information for agencies, organizations, and health care providers.

Efforts were made to collect information from as wide a spectrum of Persons Living with HIV/AIDS (PLWH) in King County as possible, ranging from individuals who are HIV positive but not yet symptomatic to persons with end-stage illness. Traditionally under-served populations of

PWLH were given particular focus, including women, persons of color, persons with histories of homelessness, mental illness, chemical dependency and/or incarceration, and youth/young adults.

The 2003 needs assessment also included efforts to develop quantitative estimates of the number of PLWH in King County who were not engaged in primary care. In early 2003, Public Health – Seattle & King County and the Washington State Department of Health (DOH) convened a workgroup across Titles I and II, comprised of grantee staff, health planners and epidemiologists from Public Health and the Washington State Department of Health. The group adapted a framework for calculating unmet need for primary care that was developed for HRSA by a team from the University of California, San Francisco (UCSF). Staff from DOH conducted overall analyses for Washington State and secondary analyses to determine estimates specific to King County and the Seattle EMA.

This HIV/AIDS Needs Assessment provides a "snapshot" of community services, priorities, and gaps as identified by consumers and providers in 2003. By nature, needs assessment processes must be ongoing to reflect the changing nature of the service delivery system, treatment advances, funding availability, and epidemic trends. Public Health - Seattle & King County, in conjunction with the Planning Council, is currently planning future needs assessment projects that will augment the findings of this most recent process.

## B. Methods

Several strategies were employed to solicit input in the needs assessment process:

- creation and distribution of written surveys to PLWH throughout King County (483 valid surveys returned);
- creation and distribution of written surveys to providers of HIV-related services throughout King County, including medical care, dental care, mental health therapy, substance use treatment, and a wide range of support services (182 valid surveys returned);
- key informant interviews with 34 service providers;
- focus groups conducted with 10 sub-populations of PLWH (66 PLWH participating), and
- mathematical analysis and modeling of data related to HIV case reporting and lab reports on T-cells tests and viral loads, in order to develop estimates of PLWH "not in care."

Public Health - Seattle & King County (Public Health) has conducted several other needs assessment processes related to HIV/AIDS care services during the past two years. These include:

- The 2002 "Gatekeeper" Project, that involved interviews with agencies and service providers

external to the HIV Continuum of Care to find out if they are serving PLWH and referring them into the Continuum;

- "Care Project 2002," a consumer interview project focusing on how issues of race/ethnicity, sex, and immigration status effect access to and satisfaction with key services (medical care, case management, housing assistance and housing related services, mental health counseling and substance use treatment);

- The 2001 Comprehensive Needs Assessment, that employed similar data-gathering strategies as the current process to identify consumer- and provider-identified service utilization, service priorities, gaps in services, and barriers to accessing services;

- The 2000 "Not in Care" Interview Project, a focused assessment process conducted by the Planning Council and Public Health, that attempted to interview PLWH who, for whatever reasons, were not accessing primary outpatient medical care for their HIV infection, and

- The 2000 HIV/AIDS Care/Prevention Collaboration Project, that explored (1) whether HIV prevention providers in Seattle-King County appropriately refer their HIV+ clients into care services and (2) whether HIV care service providers discuss sex and drug use risk reduction with clients and/or make appropriate referrals for clients with ongoing risk reduction needs.

For further information on any of these former assessments, please contact Public Health's HIV/AIDS Program at (206) 296-4649.

## C. General Findings from the 2003 Needs Assessment

As in previous assessments, most service providers report that their caseloads are comprised primarily of gay, white men. This is particularly true for private medical providers and staff at most of King County's AIDS service organizations.

Over the past decade, however, provider survey respondents from across the Continuum of Care report seeing increasing percentages of clients from other populations. The most significant changes include increases in the percentage of clients who are persons of color (29% in 2001; 35% in 2003), clients who live outside of Seattle (23% in 2001; 29% in 2003), clients who are primarily speakers of languages other than English (6% in 2001; 11% in 2003) and clients who are men who have sex with men and are also injection drug users (MSM/IDU) (9% in 2001; 13% in 2003).

The percentage of clients among other populations seems to have remained relatively constant or slightly, but not significantly, decreased. This includes the percentage of clients reported by providers who are women (18% in 2001; 15% in 2003), heterosexual injection drug users (15% in 2001; 13% in 2003), clients who have been homeless in the past year (15% in 2001; 13% in 2003), and clients who have been incarcerated in the past year (11% in 2001; 10% in 2003).

Although the percentage of clients reported as being dually and/or triply diagnosed (with HIV, mental illness and/or chemical dependency) has remained relatively constant in the past two years, providers noted that the severity of these co-morbidities has increased.
Providers report that the majority of their clients have good access to primary medical care and HIV medications. Although most clients are responding well to the treatments, providers report that they are seeing more clients who are entering care late in their HIV diagnosis and are already ill. Providers also noted increasing trends in the number of clients are not responding as well to their HIV medications as they did several years ago. This translates into increased morbidity and mortality. Although AIDS-related mortality statistics have remained relatively constant since 1998, providers from several of the County's larger programs note that client deaths are up from an average of one or two per month several years ago, to three or four per month in 2003.

Providers also reported increases in the numbers of clients who are presenting with mental illness. Each of the 34 providers interviewed as part of the key informant interview process noted that depression is on the rise among their clients. In many cases, clients who are in need of mental health counseling do not access this service due to cultural norms and/or personal denial and resistance. Providers also reported that more clients with severe mental illness continue to enter the HIV care service system, including increasing numbers of clients with personality disorders and psychoses.

Substance abuse also continues to be a significant concern among King County PLWH. Although the percentage of clients reported with substance abuse issues has remained fairly constant, providers noted that substance use problems have become more severe in the past few years. Of particular note is the increasing frequency of crystal methamphetamine use among female PWLH, a drug that was previously used almost exclusively by MSM.

Providers also noted that they are seeing an increase in the number of clients for whom English is not their primary language. In 1999, providers reported than an average of 3% of their caseloads were primarily Spanish speaking. In 2001, that figure had risen to 5%. By 2003, providers report that an average of 7% of their clients is primarily Spanish speaking. Providers also continue to report seeing increasing numbers of African refugee PLWH, particularly clients from Ethiopia and Eritrea.

In general, consumer survey respondents reported similar utilization rates for most services in the King County Continuum of Care as were reported in 2001. Ninety-four percent of consumers reported current utilization of primary medical care. Seventy-seven percent were currently using case management services, 71% reported using the Washington State AIDS Drug Assistance Program (ADAP) and 67% reported using dental care services. Providers noted an increase in service utilization among several client sub-populations who had previously been less likely to engage in care. These include foreign-born PLWH, non-English speakers, and persons with histories of homelessness and/or incarceration.

## D. Service Priorities

Consumers ranked primary medical care as the highest service priority (services they felt were most important to their health), followed by dental care, the AIDS Drug Assistance Program, case management, and housing services. For most service categories, consumer priorities changed little between 2001 and 2003. The most significant increases were noted in the percentage of consumers who prioritized the AIDS Drug Assistance Program (59% of consumers ranking this service as a priority in 2003, versus 40% in 2001) and emergency financial assistance (up from 31% of consumers in 2001 to 48% in 2003). Consumers were also significantly more likely to prioritize case management in 2003 (57% versus 50% in 2001). The only services which consumers were significantly less likely to prioritize in 2003 were client advocacy (down from 35% in 2001 to 22% in 2003), alternative therapies (29% in 2001; 23% in 2003) and home health care (9% in 2001; 5% in 2003).

Several differences emerged in the ways in which consumer sub-populations prioritized services:

- IDU PLWH were significantly more likely than other consumer populations to prioritize case management, food/meal programs, and day/respite care;
- Female PLWH were significantly more likely than males to prioritize psychosocial support, peer or client advocacy and child care;
- African American consumers were significantly more likely to prioritize emergency financial assistance and child care;
- Latino/a PLWH were significantly more likely to prioritize housing assistance and treatment adherence support programs, and
- Consumers with recent or current histories of homelessness were more likely to prioritize housing assistance, emergency financial assistance, and substance abuse services.

Providers ranked case management as the highest service priority for their clients, followed by the AIDS Drug Assistance Program, ambulatory medical care, mental health therapy/counseling, and housing services. Similar to previous years, providers were significantly more likely than consumers to prioritize mental health counseling (67% versus 30%) and substance use treatment (34% versus 7%). This discrepancy was noted by providers during the key informant interview process, many of whom reported increasing severity of dual and triple diagnoses (HIV/mental illness/chemical dependency) among their client populations, coupled with consumer resistance to and/or lack of access to these services.

The most significant increases in provider-identified priorities occurred in the categories of the AIDS Drug Assistance Program (up from 55% of providers who prioritized the service in 2001 to 76% in 2003), health insurance (23% in 2001; 39% in 2003), case management (68% in 2001; 81% in 2003) and adult day health programs (18% in 2001; 31% in 2003). Services that were significantly less likely to have been prioritized by providers in 2003 included substance abuse services (49% in 2001; 34% in 2003), client advocacy (39% in 2001; 24% in 2003), treatment adherence support (27% in 2001; 14% in 2003) and home health care (16% in 2001; 4% in 2003).

## E. Service Gaps

Consumers identified lack of access to emergency financial assistance as the number one service gap (services which consumers stated they needed, but could not get). One-third of survey respondents identified this gap. Among the sub-components of this service category, 27% of respondents identified a gap in accessing grocery vouchers and 21% identified a gap in help paying for utilities.

The only other services that were ranked as a gap by more than a 20% of survey respondents were housing assistance/housing related services and psychosocial support. Within the housing category, 21% of consumers identified a gap in rental assistance and 12% reported that they needed but could not get help in finding housing. The largest gap in psychosocial support was in one-on-one peer support (16%), followed by gaps in support groups (8%) and spiritual and religious counseling (8%). Other services that ranked among the top five service gaps for consumers were legal services and alternative therapies.

For most service categories, consumer gaps changed little between 2001 and 2003. The most significant increase was noted in the percentage of consumers who identified gaps in emergency financial assistance (34% of consumers identifying this gap in 2003, versus 24% in 2001). In 2003, consumers were also significantly more likely to identify gaps in legal services (18% versus 11% in 2001), child care (7% versus 1%) and housing assistance and housing related services (24% versus 19%). The sole service category in which consumers were significantly less likely to identify gaps in 2003 was client advocacy (down from 20% of consumers saying they "needed, but could not get" this service in 2001 to 14% in 2003).

Several differences emerged in service gaps identified by consumer sub-populations:

- Female PLWH were significantly more likely than males to identify gaps in transportation and child care;
- African American consumers were also significantly more likely than other populations to identify gaps in transportation and child care;
- Latino/a PLWH were significantly more likely to identify gaps in client advocacy, legal services, mental health services, food/meal programs, child care, and health education/risk reduction programs;
- Consumers with recent or current histories of homelessness were more likely to identify gaps in emergency financial assistance, housing assistance, oral health care, food/meal programs, transportation, and child care;
- Consumers with recent or current histories of incarceration were more likely to identify gaps in legal services and substance abuse services.

The service that providers most frequently identified as lacking for their clients was housing assistance/housing related services, noted as a service gap by 58% of providers. Within this category, 39% of providers noted that a substantial proportion of their clients needed but could not get help finding housing. Thirty-six percent of providers stated their clients could get not help paying rent.

Other services that emerged among the top five provider-identified service gaps included substance abuse services, mental health services, dental care, and emergency financial assistance and psychosocial support. In the category of substance abuse services, providers reported similar gaps in injection drug use counseling/treatment (32%) and counseling/treatment for other drugs and alcohol (30%). Help paying utility bills accounted for the largest gap in the emergency financial assistance category (25% of providers identifying this service as lacking).

## F. Unmet Need for Medical Care

As in previous years, outpatient medical care continues to be identified as a gap by a very small number of consumers. Only 2% of survey respondents (9 out of 483) stated that they needed but could not access outpatient medical care. Eight percent of consumers reported that they needed but could not access Washington State's AIDS Drug Assistance Program.

Only 5% of providers noted gaps in access to medical care for their clients. However, 16% of providers stated that a substantial number of their clients needed, but could not get assistance from the Washington State AIDS Prescription Drug Program. This represents a three-fold increase from the 2001 survey, in which only 5% of providers identified this gap for their clients.

In general, consumer focus group participants reported very few problems accessing medical care in King County. Consumers noted that medical care was available to them and their peers when they chose to access it and that the quality of care they received was excellent. The very small number of consumers who were not currently using medical care or taking HAART medications stated that this was by personal choice. Focus group participants did note several key barriers that may impede their peers from accessing medical care, including severe substance abuse, chronic mental illness, cultural norms against seeking medical care unless one is acutely ill, and denial about one's HIV risk.

In early 2003, a workgroup comprised of staff from Public Health – Seattle & King County and the Washington State Department of Health (DOH) convened to develop quantitative estimates of the number of PLWH in King County who were aware of their HIV status but not receiving medical care. The group adapted a framework for calculating unmet need for primary care that was developed for HRSA by a team from the University of California, San Francisco (UCSF). Staff from DOH conducted overall analyses for Washington State and secondary analyses to determine estimates specific to King County and the Seattle EMA.

At its first meeting, the workgroup agreed to adopt the UCSF definition of "in care": evidence of a CD4 count, viral load test or administration of HAART therapy within the previous twelve-month period. Persons determined to be "not in care" were those for whom no evidence existed of any of these three clinical markers during the prior year.

The group used data from several sources in making its estimates. Primary data for estimating statewide and local HIV prevalence came from the HIV/AIDS Reporting System (HARS). To

determine PLWH who were "not in care," the group used data from lab reporting records of CD4 and viral load tests. These data are estimated to be over 95% complete. An adjustment was made on all preliminary data to address the fact that laboratory reporting in Washington State excludes CD4 counts above 200 and undetectable viral loads. Data from the Adult Spectrum of Disease (ASD) study demonstrate that 27.6% of patients in 2000 and 2001 had only non-reportable lab results. As a result, data on care patterns was adjusted to account for patients with non-reportable lab results.

Based on these analyses, it is estimated that 76.1% of King County PLWH who are HIV+ and aware of their serostatus are in care and 23.9% of PLWH meet the UCSF definition of being "not in care." The "not in care" estimate represents 1,409 PLWH (95% confidence interval: low estimate of 1,336; high estimate of 1,484).

Sub-population analyses were conducted based on sex, race/ethnicity and HIV/AIDS status. Analyses revealed no statistically significant differences in "not in care" status based on these demographic indicators. The workgroup intends to devise methods to incorporate analyses based on other demographic characteristics in upcoming "not in care" estimates.

# II. Epidemiological Profile of HIV/AIDS in Seattle-King County

**NOTE: The following section has been excerpted from an article that appeared in the HIV/AIDS Epidemiology Report – 1st Half '03 (published jointly by Public Health – Seattle & King County and the Washington State Department of Health). For more in-depth information about the epidemiology of HIV/AIDS in King County and Washington State, please refer to these and other publications produced by the aforementioned programs. Information can also be obtained on Public Health's website at** www.metrokc.gov/health/apu.

## A. King County AIDS Rates Compared with State and National Data

AIDS case data have been collected nationally and locally since 1981 but describe only persons with advanced HIV disease. Reporting of all stages of HIV infection was implemented in Washington in September 1999. The analyses below are for all King County residents reported with HIV or AIDS through December 31, 2002.

The latest published Centers for Disease Control and Prevention AIDS data[1] show that in 2001, the Seattle metropolitan statistical area (MSA) ranked 24th in the cumulative number and 40th in annual rate of reported AIDS cases nationally. This was among 104 metropolitan areas of one-half million population or higher. The Seattle MSA (which includes King, Snohomish and Island counties) AIDS rate during 2000 was 14.3 cases per 100,000 population.

The five highest rates in the country were in New York City (65.9), Miami (53.8), Baltimore (50.0), Jersey City (42.1), and Fort Lauderdale (41.3). In comparison to the Seattle MSA rate of 14.3, the Tacoma MSA had a rate of 9.3, while the Portland MSA rate was 11.2 per 100,000.

The Seattle MSA cases make up a decreasing proportion of total U.S. AIDS cases as the epidemic move from urban to more rural areas. Seattle accounted for 1.01% of the U.S. total at the end of 1992, 0.95% at the end of 1996, and 0.81% at the end of 2001.

King County has the highest rate of HIV/AIDS among all Washington counties. About one-third of the Washington population resides in King County, but almost two-thirds of all AIDS cases resided in King County at the time of their AIDS diagnosis. Within King County the rate is highest in the city of Seattle.

## B. Diagnoses of AIDS and Deaths

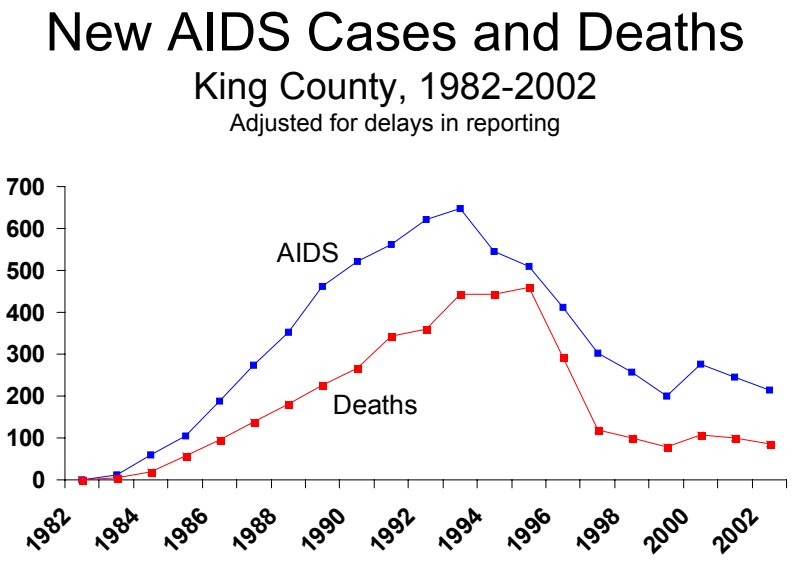
Between 1982 and December 31, 2002, a total of 6,679 King County residents have been diagnosed and reported with AIDS and 3,821 (57%) have died. Following the pattern seen nationally, AIDS cases peaked in 1993, declined through 1997, and have been stable at about 250 cases each year from 1998 to 2002 (see figure on Page 10). The number of HIV and AIDS deaths peaked from 1993 to 1995 at over 400 deaths per year, but declined to about 100 deaths annually from 1998 through 2002.

The significantly lower death numbers and delays in progression from HIV infection to AIDS beginning about 1995 are primarily due to widespread introduction of antiretroviral treatments. In addition, effective prophylaxis to prevent opportunistic infections (such as *Pneumocystis carinii* pneumonia), better monitoring of HIV progression (such as by assays of HIV viral load), and prevention efforts in reducing HIV transmission rates have contributed to decreased numbers of HIV and AIDS diagnoses.

After steep declines, the AIDS death and case numbers have been level since 1998. There are a variety of reasons that case numbers have leveled:

- persons learning their HIV status too late in the course of their HIV disease to receive optimal treatment,
- persons who experience problems accessing treatment, or who may refuse treatment,
- treatment failures due to problems with taking the medicines, adverse side effects, or the development of HIV strains resistant to currently available antiretroviral drugs.

Also, as persons with long-standing HIV infection age, they die more frequently of conditions unrelated to their HIV infection. For example, chronic hepatitis, substance abuse, and mental illness contribute significant morbidity and mortality among this aging population.




HIV/AIDS was the leading cause of death among 25-44 year old males in King County during the years 1989 to 1996[2] but dropped to the 6th leading cause of death in 2001.

While both AIDS cases and deaths numbers have decreased, more King County residents than ever are living with AIDS. There are about 250 new AIDS diagnoses each year, relative to about 100 new deaths reported.

## C. Number of Persons Infected With HIV

Because effective treatments have dramatically slowed progression of HIV disease and reduced the numbers of deaths, AIDS numbers no longer accurately portray natural changes in the epidemic. To assess the ongoing changes in the overall epidemic we analyzed all reports of HIV infection and AIDS. Public health departments in Washington began collecting case reports of HIV infection in September 1999.

As of December 2001, the Washington State Department of Health estimated that as many as 13,000 Washington residents are infected with HIV, including persons with AIDS[3]. Since 64.4% of reported HIV and AIDS cases statewide are residents of King County, we estimate 8,400 King County residents currently living with HIV infection or AIDS.

The 8,400 HIV-infected King County residents include about 3,000 persons living with AIDS and 5,400 persons living with HIV but not AIDS. These include 2,852 AIDS cases and 2,111 HIV cases reported to Public Health, an estimated 1,200 HIV diagnoses not yet reported (because reporting is relatively new), and perhaps 2,100 persons who are unaware of their infection status. CDC estimates that one-quarter to one-third of all HIV infected persons in the U.S. are undiagnosed and unaware of their status[4]. An additional 3,821 persons diagnosed with HIV or AIDS in King County have died over the past two decades.

## D. Trends in Diagnosis of HIV Infection

Pubic Health conducted analysis of trends based upon the year of initial diagnosis with HIV infection, whether that diagnosis occurred soon after infection, or at the time AIDS symptoms developed (Table 1). Although HIV reporting data are still incomplete, the number of new diagnoses appears roughly level at 400-500 new diagnoses each year since 1998.

Based upon data reported through December 2002, the characteristics of persons first diagnosed with HIV infection during 1994-1996 were compared to those diagnosed from 1997-1999, and those from 2000-2002. A chi-square test for trend was used to determine if the change in proportions for each group was statistically significant over these three time periods. The statistically significant changes shown in Table 1 may demonstrate shifts in the epidemic, artifacts from implementing surveillance for HIV infection in 1999, or longer delays in getting tested among some population groups.

Although the relative ranking of each group has not changed over time, there have been substantial shifts in the proportion of persons newly diagnosed with HIV infection among different sub-groups. Between the three year periods of 1994-96 and 2000-2002, the proportion of cases increased for heterosexual transmission (from 5% to 12%), females (from 8% to 12%), African Americans (from 14% to 22%), and residents of communities south or west of Seattle (from 8% to 11%). The proportion of cases decreased among men who have sex with men (from 72% to 62%), males (from 92% to 88%), whites (from 73% to 62%), and American Indians (from 3% to 1%).

## Table 1. Demographic characteristics and year of HIV diagnosis for 8,936 Seattle/King County residents reported to Public Health -- Seattle & King County through 12/31/2002*

| | 1982-1987 | | 1988-1990 | | 1991-1993 | | 1994-1996 | | 1997-1999 | | 2000-2002 | | Trend** |
|---|---|---|---|---|---|---|---|---|---|---|---|---|---|
| | No. | % | No. | % | No. | % | No. | % | No. | % | No. | % | 1994-2002 |
| **TOTAL** | **1615** | **100** | **2028** | **100** | **1885** | **100** | **1361** | **100** | **1004** | **100** | **1043** | **100** | |
| **HIV Exposure Category** | | | | | | | | | | | | | |
| Men who have sex w/men (MSM) | 1261 | 78 | 1597 | 79 | 1387 | 74 | 977 | 72 | 681 | 68 | 642 | 62 | Down |
| Injection drug user (IDU) | 70 | 4 | 102 | 5 | 130 | 7 | 94 | 7 | 61 | 6 | 77 | 7 | Level |
| MSM-IDU | 204 | 13 | 221 | 11 | 197 | 10 | 107 | 8 | 79 | 8 | 76 | 7 | Level |
| Blood product exposure | 34 | 2 | 31 | 2 | 17 | <1 | 7 | <1 | 5 | <1 | 7 | <1 | Level |
| Heterosexual contact | 23 | 1 | 43 | 2 | 92 | 5 | 64 | 5 | 69 | 7 | 129 | 12 | Up |
| Perinatal exposure | 5 | <1 | 3 | <1 | 8 | <1 | 7 | <1 | 3 | <1 | 2 | <1 | Level |
| *SUBTOTAL-known risk* | *1597* | | *1997* | | *1831* | | *1256* | | *898* | | *933* | | |
| Undetermined/ other | 18 | 1 | 31 | 2 | 54 | 3 | 105 | 8 | 106 | 11 | 110 | 11 | |
| **Sex & Race/Ethnicity** | | | | | | | | | | | | | |
| **Male** | 1569 | 97 | 1940 | 96 | 1763 | 94 | 1249 | 92 | 896 | 89 | 914 | 88 | Down |
| White Male | 1387 | 86 | 1637 | 81 | 1429 | 76 | 947 | 70 | 630 | 63 | 607 | 58 | Down |
| Black Male | 87 | 5 | 168 | 8 | 175 | 9 | 154 | 11 | 123 | 12 | 171 | 16 | Up |
| Hispanic Male | 59 | 4 | 81 | 4 | 107 | 6 | 96 | 7 | 103 | 10 | 95 | 9 | Up |
| Asian / PI Male | 20 | | 32 | | 37 | | 25 | 2 | 25 | 2 | 29 | 3 | Level |
| Am Indian Male | 16 | | 22 | | 15 | | 26 | 2 | 13 | 1 | 8 | 1 | Level |
| Unknown race Male | 0 | 0 | 0 | 0 | 0 | 0 | 1 | <1 | 2 | <1 | 4 | <1 | |
| **Female** | 46 | 3 | 88 | 4 | 122 | 6 | 112 | 8 | 108 | 11 | 129 | 12 | Up |
| White Female | 32 | 2 | 52 | 3 | 67 | 4 | 47 | 3 | 43 | 4 | 44 | 4 | Level |
| Black Female | 12 | <1 | 25 | 1 | 36 | 2 | 42 | 3 | 52 | 5 | 63 | 6 | Up |
| Hispanic Female | 1 | <1 | 2 | <1 | 9 | <1 | 11 | <1 | 5 | <1 | 15 | 1 | Level |
| Asian / PI Female | 0 | 0 | 4 | <1 | 3 | <1 | 4 | <1 | 3 | <1 | 2 | <1 | Level |
| Am Indian Female | 1 | <1 | 5 | <1 | 7 | <1 | 8 | <1 | 3 | <1 | 4 | <1 | Level |
| Unknown Race Female | 0 | 0 | 0 | 0 | 0 | 0 | 0 | 0 | 2 | <1 | 1 | <1 | |

**Table 1 (continued)**

| | 1982-1987 | | 1988-1990 | | 1991-1993 | | 1994-1996 | | 1997-1999 | | 2000-2002 | | Trend** 1994-2002 |
|---|---|---|---|---|---|---|---|---|---|---|---|---|---|
| | No. | % | No. | % | No. | % | No. | % | No. | % | No. | % | |
| **TOTAL** | **1615** | **100** | **2028** | **100** | **1885** | **100** | **1361** | **100** | **1004** | **100** | **1043** | **100** | |
| **Race/Ethnicity** | | | | | | | | | | | | | |
| White, not Hispanic | 1419 | 88 | 1689 | 83 | 1496 | 79 | 994 | 73 | 673 | 67 | 651 | 62 | Down |
| Black, not Hispanic | 99 | 6 | 193 | 10 | 211 | 11 | 196 | 14 | 175 | 17 | 234 | 22 | Up |
| Hispanic | 60 | 4 | 83 | 4 | 116 | 6 | 107 | 8 | 108 | 11 | 110 | 11 | Up |
| Asian / Pacific Islander | 20 | 1 | 36 | 2 | 40 | 2 | 29 | 2 | 28 | 3 | 31 | 3 | Level |
| American Indian / Alaska Native | 17 | 1 | 27 | 1 | 22 | 1 | 34 | 3 | 16 | 2 | 12 | 1 | Down |
| Unknown | 0 | 0 | 0 | 0 | 0 | 0 | 1 | <1 | 4 | <1 | 5 | <1 | |
| **Age at diagnosis of HIV** | | | | | | | | | | | | | |
| 0-19 years | 38 | 2 | 34 | 2 | 25 | 1 | 21 | 2 | 19 | 2 | 13 | 1 | Level |
| 20-29 | 569 | 35 | 539 | 27 | 489 | 26 | 311 | 23 | 234 | 23 | 219 | 21 | Level |
| 30-39 | 682 | 42 | 932 | 46 | 835 | 44 | 605 | 44 | 472 | 47 | 492 | 47 | Level |
| 40-49 | 248 | 15 | 384 | 19 | 407 | 22 | 313 | 23 | 212 | 21 | 244 | 23 | Level |
| 50-59 | 65 | 4 | 102 | 5 | 110 | 6 | 95 | 7 | 55 | 5 | 63 | 6 | Level |
| 60+ | 13 | 1 | 37 | 2 | 19 | 1 | 16 | 1 | 12 | 1 | 12 | 1 | Level |
| **King County Residence** | | | | | | | | | | | | | |
| City of Seattle | 1405 | 87 | 1818 | 90 | 1611 | 85 | 1156 | 85 | 854 | 85 | 867 | 83 | Level |
| North and East King County | 100 | 6 | 100 | 5 | 135 | 7 | 96 | 7 | 61 | 6 | 58 | 6 | Level |
| South and West King County | 110 | 7 | 110 | 5 | 139 | 7 | 109 | 8 | 89 | 9 | 118 | 11 | Up |

*Includes persons who later developed AIDS

**Indicates a statistically significant (p<.05) trend in the proportion of cases by 3-year interval between 1994 and 2002

These shifts may be related in that much of the heterosexual transmission increase seen is among African American females from south and west of Seattle, while most of the decrease is among white MSM residing in Seattle. The proportion of cases increased among black females (from 3% to 6%), black males (from 11% to 16%), and Hispanic males (from 7% to 9%), and decreased among white males (from 70% to 58% of the total).

## E. Persons Living with HIV or AIDS, by Gender, Race / Ethnicity, and Exposure Category

The trends described in the section above must be placed in the context of overall group rankings. Ninety-one percent of persons living with HIV or AIDS in King County are male and 9% are female. Seventy-three percent are White, 15% are Black, 8% Hispanic, 2% Asian or Pacific Islander (API), and 2% Native American or Alaskan Native (NA/AN). (Table 2)

Six percent of cases have no identified behavioral exposure to HIV (using the standard CDC-defined categories). Among cases with known exposure, 70% are men who have sex with men (MSM), 7% are MSM who also inject drugs (MSM-IDU), 9% are injection drug users (IDU),

6% report having a heterosexual partner with HIV or at risk of HIV infection, 1% were born to HIV-infected mothers, and 1% report receipt of blood products (mostly prior to 1985 in the US, or more recently in other countries where effective blood screening has not been implemented).

The distribution of exposure categories differs by race and gender. MSM exposure is most common among all males, accounting for 85% of known exposures among White men, 60% among Black men, 78% among Hispanic men, 85% among API men, and 51% among NA/AN men. MSM-IDU is the second most common exposure among White men (11%), API men (5%), and NA/AN men (33%). IDU is second among Black men (15%), and Hispanic men (11%).

Heterosexual transmission is the most common exposure among almost all women, including Whites (59%), Blacks (62%), Hispanics (81%), and API (71%). Among the relatively few NA/AN female cases, IDU is the most common risk behavior (78%), while 22% had heterosexual partners at risk.

While most diagnoses were among white males, the infection rates per 100,000 population show a higher burden of impact on several groups. The rate among males (537.7) is about ten times higher than among females (53.5). Compared with Whites (285.1), the rates are 2 and one half times higher among Blacks (731.9), and 1 and one half times higher among NA/AN (485.2) or Hispanics (432.6); but much lower among API (51.4). Overall rates are highest among Black and Hispanic males, and lowest among API, White, and Hispanic females.

**Table 2. King County residents living with HIV or AIDS and reported to Public Health -- Seattle & King County as of 12/31/2002**

| | Number | | Estimated Infected | 2000* Population | Estimated Rate per 100000 |
|---|---|---|---|---|---|
| | Reported | Percent | | | |
| **TOTAL** | 5,115 | 100 | 8,400 | 1,737,034 | 294.5 |
| **RACE/ETHNICITY** | | | | | |
| White, not Hispanic | 3,732 | 73 | 6,150 | 1,309,120 | 285.1 |
| Black, not Hispanic | 770 | 15 | 1,240 | 105,205 | 731.9 |
| Hispanic | 412 | 8 | 690 | 95,242 | 432.6 |
| Asian or Pacific Islander | 108 | 2 | 180 | 210,156 | 51.4 |
| Native American or Alaskan Native | 84 | 2 | 140 | 17,311 | 485.2 |
| Unknown | 9 | <1 | N.A. | | |
| **SEX & RACE/ETHNICITY** | | | | | |
| **Male** | 4,648 | 91 | 7,630 | 864,457 | 537.7 |
| White Male | 3,538 | 69 | 5,810 | 649,271 | 544.9 |
| Black Male | 571 | 11 | 940 | 53,895 | 1059.5 |
| Hispanic Male | 376 | 7 | 620 | 51,662 | 727.8 |
| Asian or Pacific Islander Male | 95 | 2 | 150 | 101,045 | 94.0 |
| Native American or Alaskan Native Male | 62 | 1 | 100 | 8,584 | 722.3 |
| Unknown Race Male | 6 | <1 | <20 | Not applicable | Not applicable |

**Table 2 (continued)**

| | Number | | Estimated Infected | 2000* Population | Estimated Rate per 100000 |
|---|---|---|---|---|---|
| **Female** | 467 | 9 | 770 | 872,577 | 53.5 |
| White Female | 194 | 4 | 320 | 659,849 | 29.4 |
| Black Female | 199 | 4 | 330 | 51,310 | 387.8 |
| Hispanic Female | 36 | <1 | 60 | 43,580 | 82.6 |
| Asian or Pacific Islander Female | 13 | <1 | <20 | 109,111 | 11.9 |
| Native American or Alaskan Native Female | 22 | <1 | <20 | 8,727 | 252.1 |
| Unknown Race Female | 3 | <1 | <20 | Not applicable | Not applicable |
| **HIV EXPOSURE CATEGORY** | | | | | |
| Men who have sex w/men (MSM) | 3,584 | 70 | 6,310 | 30- 50,000 | 12,620-21,033 |
| Injection drug user (IDU) | 344 | 7 | 620 | 15,000 | 4133 |
| MSM-IDU | 465 | 9 | 800 | 2,500- 3,800 | 21,052-32,000 |
| Blood product exposure | 40 | 1 | 70 | Unknown | Not applicable |
| Heterosexual contact | 331 | 6 | 560 | 1,245,000 | 45 |
| Perinatal exposure | 21 | <1 | 40 | Unknown | Not applicable |
| SUBTOTAL- known risk | 4,785 | 94 | 8,400 | Not applicable | Not applicable |
| Undetermined/ other | 330 | 6 | N.A. | Not applicable | Not applicable |
| **AGE AT HIV DIAGNOSIS** | | | | | |
| 0-19 years | 126 | 2 | 210 | 434,736 | 29.0 |
| 20-24 years | 503 | 10 | 830 | 116,597 | 431.4 |
| 25-29 years | 1,022 | 20 | 1,680 | 141,795 | 720.8 |
| 30-39 years | 2,255 | 44 | 3,680 | 308,187 | 731.7 |
| 40-49 years | 943 | 19 | 1,560 | 292,470 | 322.4 |
| 50 years and over | 266 | 5 | 440 | 443,249 | 60.0 |
| **RESIDENCE AT DIAGNOSIS** | | | | | |
| City of Seattle | 4,388 | 86 | 7,230 | 563,374 | 778.9 |
| North or East of Seattle | 300 | 6 | 500 | 575,548 | 52.1 |
| South or West of Seattle | 427 | 8 | 670 | 597,999 | 71.4 |

* 2000 Census Population as of April 1, 2000, with single race bridged estimates

## F. Persons Living with HIV or AIDS, by Residence

Eighty-six percent of persons living with HIV or AIDS in King County resided in the City of Seattle at the time of their diagnosis. In contrast, Seattle is home to about 32% of the King County population. Overall, about 8% of persons with HIV/AIDS lived south or west of Seattle, and the remaining 6% resided north or east of Seattle. (Table 2)

There are a number of statistical differences (based on chi-square tests) between the HIV-infected populations inside Seattle compared with outside the city. Residents of Seattle are more likely to be male, MSM or MSM-IDU, White males, or American Indian males. Residents

outside Seattle are more likely to be female (Black, White or Hispanic) and report IDU or heterosexual exposure.

## G. Age at Diagnosis

Based upon the age at initial diagnosis of HIV infection, the largest numbers of King County residents reported with HIV were age 25-29 (20%), age 30-34 (24%), or age 35-39 (20%). Only 2% of persons were under age 20. This distribution has remained largely unchanged throughout the epidemic.

The age distribution is different among males and females. Females tend to be much younger than males when first diagnosed with HIV. This is probably because most women are heterosexually infected and may tend to be younger than their male partners.

## H. Conclusions

There are an estimated 8,400 HIV-infected King County residents. These include 3,000 persons with AIDS and 5,400 persons with HIV who have not yet developed AIDS. Another 3,800 persons have died since 1982. The numbers of deaths and new AIDS diagnoses have declined substantially in recent years primarily due to effective treatments. Since 1998, the numbers of new cases and deaths appear to have leveled, with about 100 deaths and about 250 new AIDS cases reported each year.

About 400-500 new HIV infections have been diagnosed each year since HIV reporting was implemented in Washington State in 1999. However it is important to note that many persons with HIV infection learn about their infection late in the course of their disease because they had not been tested until they developed symptoms of AIDS.

The total number of persons living with AIDS or with HIV infection in King County is increasing because each year there are more new diagnoses than deaths. Most HIV-infected King County residents currently are White men who have sex with men, are 30-45 years of age, and reside in Seattle. However, based upon the date of initial diagnosis with HIV infection, an increasing proportion of cases are Black males or Black females, and the proportion of cases due to heterosexual transmission is also increasing.

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Footnotes

1. CDC. HIV/AIDS Surveillance Report, Volume 13(2), Cases reported through December 2001. Available at http://www.cdc.gov/hiv/stats/hasrlink.htm
2. King County Registrar / VISTA
3. HIV Prevalence Estimation in Washington (working document)
4. Sweeney PA, Fleming PL, Karon JM, et al. A minimum estimate of the number of living HIV infected persons confidentiality tested in the United States [Abstract I-16]. In: Program and Abstracts of the Interscience Conference on Antimicrobial Agents and Chemotherapy.

Toronto, Canada: American Society for Microbiology, September 1997.

# III. Methods

The needs assessment process used several strategies to gather input from persons living with HIV/AIDS (PLWH) in King County and providers of services to this population. The centerpiece of the process was the creation and distribution of written surveys to PLWH throughout King County. Other components of the needs assessment process included a written service provider survey, focus groups of targeted consumer sub-populations and key informant interviews with service providers.

## A. Consumer Surveys

The 2003 consumer survey targeted persons living with HIV/AIDS throughout King County. (See Appendix B for a copy of the consumer survey instrument.) The HIV/AIDS Planning Council's Needs Assessment Work Group oversaw the development of the survey instrument, and staff from Public Health – Seattle & King County were responsible for survey distribution, collection and analysis.

The Planning Council sought to collect information on a wide spectrum of PLWH in King County, ranging from individuals who were HIV positive but not yet symptomatic to persons with end-stage illness. The process emphasized traditionally under-served populations, including PLWH with histories of homelessness, mental illness, chemical dependency and/or incarceration, women, youth/young adults, persons of color and persons living in South and East King County. Survey forms were created in both English and Spanish language versions.

The survey inquired about 32 types of HIV/AIDS-related services offered in the King County Continuum of Care. Consumers identified each service either as one that they used, did not need/want, or needed but could not get. For each service that consumers used, the survey asked, "If you use this service, how well does it meet your needs?" Consumers were asked to use a Likert scale ranging from "1" (not at all) to "5" (completely) to describe how well each service meet their specific needs. The survey also asked consumers to choose up to seven of the 32 services that they would consider most important in helping them cope with their HIV/AIDS-related health issues. Answers to these questions were used to define consumer "service priorities."

The survey also contained a new section on case management services. This section focused on consumers' experiences in using case management in King County. The survey provided a list of possible reasons why a consumer might not currently have a case manager (or may never have had one), and asked respondents to check all applicable answers. For consumers who used case management during the past year, the survey included a list of services commonly associated with case management and asked consumers if the case manager helped them access the service, was not able to help them access the service or if the service was not needed.

The final component of the survey was an extensive demographic section. This section included questions relating to general demographics (e.g., sex, age, race/ethnicity, area of residence within King County, etc.), as well as questions relating to the individuals HIV-related health status, mental health, substance use, incarceration history, homelessness and risk reduction needs.

In creating the survey instrument, the Planning Council made extensive efforts to safeguard the anonymity of survey respondents. Survey instructions explicitly stated that consumers should not include their names, addresses or phone numbers on return surveys. To further safeguard respondents' confidentiality, the surveys were pre-addressed to the "Planning Council," rather than the "HIV/AIDS Planning Council" or "Public Health – Seattle & King County." Survey forms were bar coded for pre-paid reply.

To reach as broad a range of consumers as possible, survey distribution sites included 48 service agencies, community organizations, and health care facilities throughout the county. Surveys were also distributed at the offices of 27 private medical care providers and 8 private dentists. Public Health delivered a total of 2,584 surveys to various agency and provider sites. Based on data from previous years, it is estimated that approximately 60% of surveys distributed to agencies/providers were actually distributed to consumers. The Planning Council received a total of 483 valid responses, for a return rate of between 19% and 31%.

## B. Provider Surveys

The Planning Council created and distributed a provider survey as the second component of the 2003 assessment process. The Council believes that service provider data offers important comparisons to consumer-identified service priorities and gaps, as well as helping to gather input about sub-populations that may not have been effectively represented among consumer survey respondents. (See Appendix C for a copy of the provider survey instrument.)

The survey collected information from as broad a range as possible of providers of service to PLWH in King County. These included primary care providers, case managers, providers of non-Western therapies, private dentists, substance use and mental health treatment professionals and staff from social service agencies. Public Health distributed provider surveys at 59 agencies, community organizations, and health care facilities throughout the county. Surveys were also distributed to 28 private doctors and 8 private dentists.

The survey inquired about the type of service offered by the provider, the total number of PLWH on the provider's current caseload, and demographics of the provider's HIV/AIDS clientele. Using the same list of 32 HIV/AIDS-related services that appeared on the consumer survey, providers were asked to identify up to seven services that they believed were most important in helping their clients cope with HIV/AIDS-related health issues ("service priorities"). The survey also asked providers to check each service that they felt was needed by a substantial number of their clients, but that clients were having trouble accessing ("service gaps"). Public Health delivered a total of 432 surveys to various provider sites. The Planning Council received a total of 182 valid responses, for a return rate of 42%.

## C. Consumer Focus Groups

The needs assessment process included plans for twelve focus groups to gather in-depth qualitative information from specific sub-populations of persons living with HIV/AIDS in King County. For the 2003 process, Public Health partnered with AIDS Housing of Washington (AHW) in facilitating the focus groups. During the first hour of each group, Public Health staff focused on medical care and social service issues, while AHW staff asked questions related to housing during the second hour. To better focus on the current medical care system, Public Health attempted to recruit participants who had received medical care in King County for the first time within the past five years. (NOTE: Information gathered on housing issues will be reported in the Seattle-King County HIV Housing Needs Assessment and Plan, created by AIDS Housing of Washington, and due for publication in September 2004.)

The focus group process acknowledges that specific sub-populations of PLWH may present unique utilization patterns, access barriers and service gaps, and addresses the concern that written surveys might not be as well suited to capture information from members of several of the sub-populations. A total of 66 PLWH attended the ten focus groups.

The questions posed to participants focused on:

- current utilization of medical care and associated clinical services;
- reasons, if applicable, for not currently receiving medical care;
- consumers' initial experience in accessing medical care in King County;
- problems encountered in getting medical care and other clinical services;
- the extent of medical care utilization and access problems among their peers, and
- suggestions for improving access to care in King County.

(See Appendix D for a copy of the focus group script.)

Focus groups were held with the following sub-populations of PLWH:

| | |
|---|---|
| African Americans | MSM of color |
| Homeless persons (current or in past year) | Native Americans |
| Incarcerated (current or in past year) | White MSM |
| Injection drug users | Women |
| Latinos (conducted in Spanish) | Youth and young adults |

Public Health planned two additional focus groups with Asian/Pacific Islander PLWH and men who have sex with men and were also injection drug users (MSM/IDU). Despite targeted outreach efforts and repeated attempts to re-schedule these groups, each was cancelled due to lack of participation. As a result, information regarding service utilization and needs of A/PI PLWH and MSM/IDU are limited in this report to quantitative data from consumer surveys and key informant interviews of service providers to this population.

Service providers across the Continuum of Care disseminated information about the focus groups within the targeted communities and helped to identify potential participants. Participants registered for the groups by calling a central registration hotline, with outgoing messages in both English and Spanish. Participants received $30 for their time, as well as reimbursement for transportation and/or child care expenses incurred. Food was provided at all groups. Staff recorded each of the groups on audiotape. In addition, a non-participant observer took written notes at each group to assist in the final transcription.

## D. Provider Interviews

In order to capture qualitative information about caseload demographics and service trends, staff from Public Health – Seattle & King County interviewed 34 HIV/AIDS care service providers in King County. The providers supplied general demographic information about their client population, including information about HIV-related medical trends and other co-morbidities (mental illness, substance use, etc.).

The interviews also asked providers to comment on:

- trends and changes in the kinds of services their clients are using;
- issues related to enrolling and maintaining HIV+ clients in primary medical care and related clinical services;
- problems related to access to medical care, and
- suggestions on how to overcome access barriers.

(See Appendix E for a copy of the provider interview form.)

As with the focus groups, providers were identified based on their affiliations with specific sub-populations of PLWH. The interview roster included medical providers with large HIV/AIDS caseloads (representing private, clinic and hospital-based practices throughout King County), case managers, mental health providers, substance use treatment facility staff, and jail health staff. Public Health staff also interviewed service providers at several King County community-based organizations (including organizations targeting women, persons of color, youth/young adults, and homeless persons). Each interview lasted between forty-five and ninety minutes. Although most interviews were conducted with individual providers, some providers were interviewed in pairs.